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NEW RESEARCH ON AGING: CHANGING LONG-TERM CARE NEEDS BY THE 21ST CENTURY

WORKSHOP

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

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OPENING REMARKS BY PORTIA PORTER MITTELMAN, STAFF DIRECTOR, SPECIAL COMMITTEE ON AGING

Ms. MITTELMAN. The committee will come to order.

Good morning. I would like to welcome our panel from the National Institute on Aging who is bringing you this seminar today. We hope it will be a first step toward a number of seminars of this type, so that we can get to know one another a little bit better.

I am going to turn it over to Dr. Williams and his staff this morning to make the presentation. But before I do that, there are a few people I really need to thank.

First of all, of course, Dr. Williams for allowing us to experiment with his staff. They have been wonderful, and it has been a good experience working with Dr. Williams and his staff. Also Dr. Gene Cohen, who I don't see yet this morning——

DR. FRANKLIN T. WILLIAMS, DIRECTOR, NATIONAL INSTITUTE ON AGING

Dr. WILLIAMS. He had to stay for an emergency meeting of the Institute directors on the appropriations bill.

Ms. MITTELMAN. That is very important. Dr. Gene Cohen is the Deputy Director of NIA. He has also been extremely helpful to us.

There are two other people from the NIA I would especially like to mention. I have been told that they don't want to be mentioned this morning, but they have been so tremendously helpful to the staff of the Aging Committee. First of all, Sandra Lindsey, who is the Legislative Officer for the NIA, and Freddy Carp, who is the Head of Publications for that agency.

They have been tremendous, and I want to personally thank them.

I would also like to thank a member of our staff, Heather Dreyer, who has worked very hard to put this together this morning.

Now, without further ado, I would like to turn it over to Dr. Williams.

Dr. WILLIAMS. Thank you very much, Ms. Mittelman. We want to thank you and Heather Dreyer and others of your staff who have helped guide us in preparing for this session. It has been very much a cooperative effort, as already indicated.

I am just very glad to welcome you this morning as Director of the National Institute of Aging, and to start the outlining of our mission, and lead on into reports from our staff on our accomplishments and our goals, of which we certainly consider are extremely important to the total health of our country, explicitly to older

people. What happens to older people is important to everyone else, also. So we consider these national priorities, not just local to any one segment.

The National Institute of Aging was established by Congressional mandate in 1974 with a mission to conduct and support biomedical, social and behavioral research and research training relating to aging processes, and the diseases and other special problems and needs of older people. These are very broad research mandates, which we have tried to live up to, and to pay attention to all aspects of this. I might just point out that our mandate is probably the broadest of any of the Institutes at NIH.

In terms of our approach of priorities, we try to approach them in two ways. First, we look at the scientific readiness across this broad frontier I have mentioned, and try to see where the opportunities are that are most likely to be successful in terms of supporting new scientific endeavors. Second, we try to see what the priorities of our society are, what the issues are that society sees as being of the most importance in relation to aging and the problems. So we have a range of guidance in terms of setting our priorities of older people.

We get constant feed-in from all segments of the public. We do a great deal of information providing to the public and feedback. But of course, most importantly, we get our guidance from Congress, from the Congressional staff and members, and from our own National Advisory Council on Aging. The National Advisory Council is composed of public and private leaders who meet regularly and give us their guidance on what should be our highest priorities. So we have a range of guidance in terms of setting our priorities. I want to take a moment to indicate what we consider our priorities to be. In the handouts you have, there are a couple of things I want to call your attention to. There is a folder headed "NIA" that we may come back to describe some of our mechanisms. Most importantly, for my comments now, right behind the folder is a red-lined sheet that says "National Institute of Aging." On the back side of that is a list of our current views about our priorities. I just want to touch briefly on these to orient you to some of the discussions we are going to take up later.

In a little different order than what is shown here, I want to point out that our basic priority is understanding aging and recognizing the differences between aging and disease or environmental or lifestyle factors that affect older people. The more we have learned, the more we have found that most people can and certainly many do live in extreme late years with good health and functioning. The possibilities are far greater than most of us recognize for contributory independent roles in later life.

Related to that is the heading of Health and Effective Functioning. Based on this concept of potential for independence, we put a log of emphasis on maintaining health, preventive measures, health maintenance measures of a variety of types, and some of those we will hear about from our program staff.

Turning from these areas of positive goals, we do address certainly the major hazards to older people, which include, in the first instance, the problems of mental frailty, specifically dementia of the Alzheimer's type. This is by far the greatest threat to independence

in our society of any disease condition. There are 4 million people that we estimate have it now. The figures are going up. The only answer to this devastating disease has to come from research. So this is a major priority of ours, and there are many promising opportunities in relation to it.

Another corollary is physical frailty. There we have been increasing our commitment to research in areas that affect physical loss of independence. That includes problems of falls, mobility, movement disorders, osteoporosis, osteoarthritis, and hip fractures. Just this year we have had a major initiative begun on what is called "FICSIT" because the aim is to fix these problems that frail older people have, with a heavy emphasis on rehabilitation as well as understanding the basic problem. There has been a very strong response to that.

Other areas we give priority include the problems of long-term care, how we can approach it more successfully, both for people who need care and the caregivers. We give a lot of emphasis to special populations, the differences between minority groups of various ethnic and cultural characteristics in our society, and the special problems of people living in rural settings, and international populations from whom we can learn special things.

I want to mention that, even though it is not technically international, on Guam, for example, one of the most promising opportunities to get at some of the causes of Alzheimer's exist because of some of the special characteristics of the population. They have a very high prevalence of Parkinson's disease associated with dementia. That's only one of a number of examples where we can learn from others around the world about the issues of aging.

Another priority is certainly training and career development. We desperately need more people who are undertaking research careers relating to aging and geriatrics. This receives a high priority in our Institute.

These are just brief listings of some of our priorities. There are a couple of cross-cutting issues that I want to mention as well, that we are giving some special attention to this year, one is pharmacology in aging. We have had a special offering of that, and that may be mentioned further later. We have over 100 applications for research support around pharmacology in aging, of which we will be able to support only a handful. We will look forward to trying to do more in the future.

Another special cross-cutting issue is that of health and retirement. We will begin a major long-term survey on the characteristics that occur as people move from pre-retirement to forced retirement status.

I would like to stop here and begin to turn to our staff, who will give details about several of our areas. I thought we would hold questions until the end. I will be calling time on each of our staff, as they tend to go too long. We will aim to have at least one-half hour at the end of our presentation for general questions.

The first presentation will be by Dr. Richard Sprott, who is the Associate Director of the Biomedical Research and Clinical Medicine Program. He will be speaking about the impact of research on the need for services.

DR. RICHARD SPROTT, ASSOCIATE DIRECTOR, BIOMEDICAL RESEARCH AND CLINICAL MEDICINE PROGRAM

Dr. SPROTT. Which is a funny way of saying I have the unenviable task of trying to somehow make the basic science less dry and more interesting.

Good morning. I would like to divide my talk into two parts which deal with two very different issues, the first of which is biomarkers of aging. Biomarkers of aging is a term that many of you are going to hear about, perhaps a little more than you want to hear about over the next couple of years. I would like to make sure you all know what is meant by the term biomarkers, both what biomarkers of aging might be, and why we care what biomarkers are.

Do me a favor for a minute, and imagine that this afternoon, you find "The Stuff"—the real elixir of life that produces lifespan extension and long and healthy life, what Ponce de Leon was looking for all those years ago. How would you prove to the rest of the world that you have done that?

The simplest way would be to take it yourself for the next 70—or depending on how old you are now, 70 or 80 or 90 years until you are 120, then come back and present yourself to the world as living proof that you really had The Stuff. The first problem is that not many of the people you originally told you had The Stuff are going to be alive to help you with this test. You will have the problem of trying to convince those people who are alive then that you are really that old and having been taking this stuff all along.

The problems with a clinical trial of any intervention which purports to produce lifespan extension or health span extension, which is perhaps more important, are very much the same. How do you keep a research team together for 100 years in order to do the research? Obviously we have to have some other approach to dealing with that problem. Right now, the limit is that there is not any other approach, other than taking the stuff for the lifespan of the organism we are looking at.

Now I will ask you to imagine a different problem. Suppose you have been asked, and some of us have, to assess the competence of pilots to continue flying, or automobile drivers to keep driving, or presidents to keep presiding, after they reach some standard age, 50, 65, 70, 80, what should it be? How do we determine whether you ought to be allowed to continue that activity or whether you have become a danger to the people around you?

We now make that judgment using either chronological age, as we do with pilots, or nothing, as we do with the other examples I cited. What we really need are real performance measures, measures other than the passage of chronological time. These too, are what I mean by biological markers of aging.

The primary objective of NIA's Biomarkers of Aging program is to develop a means to test interventions into aging processes, and to test real competence, rather than using chronological age as our best measure. The reason for that is, as I think most of us intuitively know, that chronological age is not a great measure of rate of aging.

We all have someone in our family, an Aunt Tilly or someone, who when she is 60 or 70 is in great shape. She is sharp, she continues to do all the things that are needed to maintain her independence. She drives her car, does her own shopping, is involved in the community and so on. We know she will live to a relatively long age, and she does.

We probably all also have somebody else who we know when he or she is in their late 40's or early 50's is on their way out. When they are 50, they are the equivalent of our Aunt Tilly when she was 70.

Intuitively, we know that. Most of us can think of examples of both of those kinds of people. Scientifically, we have no way to validate that knowledge. We have no real measures yet that allow us to reliably and accurately make that judgment. That is what the NIA's Biomarkers of Aging program is intended to do.

In order to develop that program, there are a few basic assumptions we have made that are central to the concept. One is, as I have just said, chronological age. It is not the best measure of aging processes itself. Two, and this is very true, not all organ systems age at the same rate. Most of you are old enough now to note that your eyes may go faster than your teeth, your feet may go faster than your cardiovascular system, and so on.

The rate of aging for the whole individual is probably the sum of the rates of aging for all those parts. But it might be that some key organ system determines the rate for the whole organism, like a cell center, for example.

Finally, another assumption is that measures of the rate of aging of organ systems can, in fact, be found. These measures, if we found them, would be what I mean by biomarkers of aging. We can then use those biomarkers of aging to assess the rate of aging in treated and nontreated individuals in a clinical trial, like the recent report in the New England Journal on the use of the growth hormone with men. There is a copy of that paper in the back of the room, by the way, if you want to pick one up on your way out.

We can also use them as performance measures, which could be used to assess the performance ability of pilots, and individuals in situations of that type. The National Institute on Aging in collaboration with the National Center of Toxicology Research in Jefferson, AR, is currently sponsoring a 10-year, $30 million program to develop biomarkers of aging. We hope that by the middle of this decade this research will produce a usable set of biomarkers that can be used in clinical settings with human beings.

At the same time, a major component of that project is the inclusion of dietary restriction as one of the key interventions for those animals. Dietary restriction is the one intervention that we know currently produces a longer lifespan, with a greater health span, delays the onset of some of the major diseases of aging in those organisms, delays the onset of cancer, and so on. So we are including that manipulation in this research. We are attempting, among other things, to understand how it is that dietary restriction produces those effects.

Now, if I can switch gears real fast, and go from something as basic as that to something much more practical, I would like to talk briefly about osteoporosis and hip fractures. It is interesting

that most of the people in this room this morning are female. I am really talking directly to you, because this is your problem. The odds are overwhelming that almost one-third of you, if you do not do some intervention yourself, will personally learn what I mean about the problems of hip fracture.

Think about the changes in your life if you were confined to a wheelchair or had to use a walker on a constant basis. Most of the activities you currently enjoy would not be possible any more. If we had more time, I would pause for you to think your way through what that really would mean to you, and we could run through the possibilities of what it would do to your interest in sports, shopping, cooking, your job, entertainment, sex, normal daily functions, and on and on. Think about all the things that would be affected by your being in that state.

Multiply that by somewhere between 100,000 and 200,000 times a year, and you have some estimate of the magnitude of this problem for the American population. There is a tremendous human cost involved in the problem of hip fractures, without regard for what it does to the health care system.

Older osteoporosis victims suffer over 200,000 hip fractures a year. Forty percent of the people who suffer a hip fracture will never recover full independence. The graphic you have just been given is what a hip fracture looks like, and I hope you leave it on your desk for the next year to remind yourself of what that looks like. I don't care if you use it as a coaster for your coffee, just keep it around for a while to remember the dimensions of that problem. The costs to the health care system of hip fractures alone, to people over 64 alone, is about $8 billion a year. If we don't do something about that, it will rise to $14 billion, in 1987 dollars, by the year 2020 or five Senate terms from today.

The real question is, can we intervene to prevent this tragic loss of function? As Dr. Williams already mentioned, one of the things we can do is deal with the fracture itself, and rehabilitation after it has occurred. That's what is going on with our "FICSIT" program. The other approach is to try and reduce the amount of osteoporosis, so that you prevent the hip fracture. If we can do that, we can prevent most of that ongoing disability.

The question is, what does it take to do it? Here I think I have a very hopeful thing to say. We believe there are several interventions that are right now ready for clinical trial. They have not taken place basically because the resources do not exist. They include exercise, drug therapy, estrogen replacement therapy. Drug therapy, by the way, is referred to in another New England Journal article which appeared on July 12, copies of which are also available in the back of the room.

Calcium supplementation and combinations of the above therapies are also being considered. There is a handout in your package called Osteoporosis and Hip Fracture, it looks like this, that gives you the details of those kinds of interventions.

These are not pies in the sky. This is not some wild promise we are making here. This stuff is ready for trial now. With adequate resources, we can begin clinical trials on those interventions within a matter of months. I really believe we can eliminate half the projected hip fractures.

This would save over $3 billion a year, and over $400 billion between now and 2020. More importantly, it would save the tremendous human cost of hip fracture that you or I are going to have. The odds are overwhelming that by the year 2020 one of the two of us will have one of those hip fractures.

Dr. WILLIAMS. Thank you, Dr. Sprott.

One in three white females in the United States under these current projections will have a hip fracture by the time she is 90.

The next presentation will be by Dr. Deborah Claman from our Neuroscience and Neuropsychology of Aging program. We will be talking about cognition and independence, and productivity of older adults.

DR. DEBORAH CLAMAN, NEUROSCIENCE AND NEUROPSYCHOLOGY OF AGING PROGRAM

Dr. CLAMAN. I am pleased to have the opportunity to be here today and tell you about some of our goals and directions.

I am aware, first of all, that your chief concern is for public policy and for programs that are going to serve the needs of older adults. What we do at NIH is research, so the first question that immediately comes to mind is how is what we do going to serve your needs?

What I want to talk about today is one particular kind of research that we believe has really strong implications for the types of services that are needed for older adults, as well as for maintaining their independence and productivity. This is the research on brain and behavior, and more specifically, on the types of changes that occur as people age, in how people see, hear, think, remember, sleep, and move about freely.

If you think about it for a minute, what are the types of complaints that older adults have? What are the types of things that affect their quality of life? They are just these kinds of problems. They complain of problems with their memory, and other cognitive functions. They complain of problems with seeing, hearing, and foods not tasting like they used to. They have problems with moving about freely. They develop tremors and shakiness, and they fall. These are exactly the kinds of problems we are talking about when we talk about brain and behavior.

The first thing we need to know is what exactly is normal, what is to be expected as people age? As Dr. Williams mentioned, we need to know what is normal age-related decrement, and what is the result of pathology, or some disease process. This is a very pragmatic concern.

Let's think about it for a minute. If you are going to develop a new kind of treatment, you have to know when you can say that it has been successful. In order to do that, you have to know what is normal, because this is the end point you will be trying to achieve with the new treatment. If you are trying to develop a new treatment for memory, for example, what you need to know is what memory is supposed to be like in a normal, 65-year-old person. Otherwise, there is no basis for any therapeutic action.

What we are discovering more and more as we conduct this type of research is that many alterations that we had previously attrib-

uted to normal aging are actually the result of various disease processes. This is very critical, because if we can specify a disease, then there is hope for remediation and treatment, and eventually for prevention and cure.

On the flip side, if we can stipulate what is normal, in terms of behavioral changes that occur with aging, then we can design appropriate therapies, or redesign the environment to better fit the needs of older adults. I will give you some examples of what I mean in a minute. This is not to deny, by the way, that some changes are inevitable as we age. For example, menopause, changes in the lens of the eye—we know these changes are inevitable. But others may not be normal. In developing appropriate therapies, we need to know about the range of normalcy.

One example of the behavior of older people that we have begun to study is sleep, and what is normal for older people. As you know, we are told that a common complaint is insomnia in older adults, and changes in their sleeping patterns, which they find very disruptive.

A fascinating paper that just came out from Pat Printz, at the University of Washington, showed that in fact healthy older adults do not report problems with their sleep. Rather, in those older adults who do have problems with their sleep, there is usually some underlying cause. They may have diseases that we are familiar with, such as arthritis, or diseases that we are not as familiar with, such as apnea or myoclonus. Often, these diseases would have gone undetected if it were not for their problems with sleep.

Another example to show you that we need better measurement techniques to tell us what is normal and what may be pathological is in the area of vision. What typically happens is that an older person feels their vision is not what it used to be, and goes to his doctor with that complaint. He tells the doctor that his vision is not quite right, or his glasses are not correcting the way they used to. So the ophthalmologist or internist places the patient in front of the eye chart or some other device and says that the patient is perfectly normal.

What typically happens next is that the person feels relieved, jumps in his car, and has an automobile accident, or he feels on the other hand that no one understands what his problem is. He retreats into a shell and becomes depressed. Let's analyze for a second what went wrong.

The problem is that the measuring techniques that are commonly used are not sensitive to the problems of older adults. What this common older adult may have been suffering from is a normal part of aging that we have begun to term "visual clutter." What visual clutter is, is being able to choose the correct images to attend to against a complicated background. This is important for things like driving and other processes that require mental alertness to visual images.

If we can detect and measure this phenomenon reliably, the next step will be to provide a prosthesis or other devices to keep older adults seeing, and mobile and independent for as long as possible.

The last example I will give you, a critical concern of people as they age, is in the area of memory. Memory problems are a common complaint, from the time we all finish formal schooling,

we begin to complain that our memory is not what it used to be. By studying what is normal in memory and aging, we have been able to learn that one of the earliest signs of abnormal memory functioning and of dementia is in older adults' rate of forgetting.

What this means is that as we age, we may not be able to learn as quickly as we used to and we should be able to remember what we've learned when we can't retain simple information over let's say, a one-half hour to an hour delay, we know that that's probably an early sign of a problem. We wouldn't be able to know that if we didn't know that most healthy older adults' rate of forgetting is not increased.

In general, our primary objective is to conduct research that will keep people out of nursing homes, mobile, independent, and productive for as long as they can be. I have given you examples of cases where we are finding out exactly what is normal in the areas of sleep, and vision and memory. As I said earlier, knowing what is normal has important implications for determining eligibility and for developing appropriate programs for older adults.

I know the arguments for services are compelling, and that research, particularly at the basic level, often seems irrelevant to social needs. But our view is that instead of starting a variety of programs that we examine what drives those needs.

Most of you will remember the epidemic in the 1950's where children were being paralyzed in large numbers by an unknown agent. If we had invested heavily at that time in building bigger and better iron lungs for the afflicted, perhaps we never would have come up with a preventative measure, a vaccine for polio. It was investment in research that eliminated the need for the majority of social services in that disease as well.

It is not that we are interested in disallowing driving in older adults, or grounding airline pilots from flying once they reach a particular age. Just the contrary.

The research we are trying to foster will give us specific, functional assessment measures based on what the range of normal functions is for older adults. What we are promoting are studies that will differentiate what is normal from what is abnormal, what is pathological in sensory, cognitive, and motor processes. Only then will we be able to design appropriate therapies or redesign the environment to compensate for age-related alterations.

Dr. WILLIAMS. Thank you very much, Dr. Claman.

I think it is very important to emphasize some of these underlying issues. As I think all of you know, we have made major commitments to research directly dealing with Alzheimer's disease where there are many promising clues that I think we can build on. We can come back to that during questions, also.

Our next presentation will be from Dr. Marcia Ory, Chief of the Social Science Research on Aging in our Behavioral and Social Research program. She will be talking about family and health care services.

DR. MARCIA ORY, CHIEF, SOCIAL SCIENCE RESEARCH ON AGING, BEHAVIORAL AND SOCIAL RESEARCH PROGRAM

Dr. ORY. Thank you.

The costs of long-term care are simply too high, for me, for you, for most of our aging population. We have heard how research can help solve the problems of hip fractures, sleep, vision, and memory.

We can also turn to research for some new solutions to the problems of long-term care. NIA's research in this area creates a knowledge base for programs and public policies.

Today I will talk about long-term care that is truly close to home—the care giving burdens that some families experience, balancing home and work life, in-home care and other alternatives to institutionalization, and elder-friendly environments to enhance independence.

We all know that most long-term care is provided by families, at tremendous emotional, physical, and financial cost. NIA research examines family care giving and strategies for reducing such burdens of care.

For example, research is beginning to describe the unique care giving burdens experienced by different family members in different circumstances—think of older spouses providing round-the-clock care, at the risk of their own health, of adult children, trying to care for their parents, while they also care for their own children, of aging parents whose disabled children are living longer than ever before. This is certainly the case with mental retardation.

Family care giving burdens are influenced by new links between formal and family care. Families must often deal with a confusing and often changing array of formal health and supportive services. For example, older people are currently being discharged from acute care settings with severe conditions that demand specialized home care. Respirators, feeding tubes, catheters, once the purview of skilled professionals, are becoming more commonplace in the home.

Just the other day I heard about an 81-year-old man who was discharged from a hospital emergency room at 4 o'clock in the morning and sent home in an ambulance with an in-dwelling catheter. His 78-year-old wife was expected to be able to maintain his in-dwelling catheter with just a few instructions provided at that hour. As you might expect, his wife, who had her own health problems, was distraught and so concerned about her husband that she was unable to follow the instructions.

Unfortunately, this is no longer a rare situation. Research is urgently needed to help families deal with the technical and emotional aspects of such high-tech care.

Let's turn to our second issue in long-term care, employed caregivers. This topic has come to the forefront with the recent Family and Medical Leave Act. While many think of this as predominantly a child care issue, elderly parents are also in need of care. Adult daughters and even sons report having to quit their jobs or take extended leave because of parent care responsibilities.

Just last week, the cover story in Newsweek was devoted to "Daughter Track." This article is full of personal stories of daughters caught between many responsibilities: care for their parents, care for their own children, and job demands.

While most families do not fall in this situation now, this will be a growing problem. Additional research is needed on balancing

work obligations and family responsibilities. How can family stress be reduced and worker productivity enhanced?

Employers such as AT&T, Stride-Rite, and Travelers have begun to design innovative programs to decrease employee care giver problems. These include the use of flexitime, referral to other services, support groups or family leave programs. Studies of such innovative employee programs can provide concrete solutions to the rapidly increasing problems of elder care.

In-home health care is another family-based way to meet long-term care problems. Many questions have been raised about the use of in-home services as an alternative to institutionalization. In-home care is popularly thought to assist families in keeping loved ones at home.

However, scientific studies show that home care, as currently delivered, is not a panacea. It does not even necessarily reduce the use of services or their costs. Families, by and large, are willing to provide extensive care, and often do so, at great sacrifice. When you ask families what they need, they invariably say "a break" or "some rest" so they can keep on caring.

Despite the reported demand for respite, we know very little about how to deliver respite services so that caregivers will actually use them, and get the intended benefits. For example, we need to learn how to design services that operate on the family schedule, not on the agency schedule.

Or consider board and care homes, another way of providing needed care to older people outside of nursing homes. These types of homes have received a lot of negative press lately. Yet one NIA-supported study reveals that many residents and their families are generally satisfied with board and care facilities. Research is needed to understand how to make board and care homes more family-like and supportive.

The need for long-term care is affected by how well older people can negotiate their environments. Not all home environments are equal for older adults. We need a detailed understanding of how older people's independence can be prolonged by adjusting their environments to their changing needs, their abilities, and their preferences. For example, bathroom doors may be too narrow for the older man with a walker or a wheelchair. The knobs on a kitchen stove may be too difficult for an older woman with arthritis to reach or turn. Home-based medical equipment is often designed without considering the older user at all.

Creating elder friendly environments that enhance older peoples' independence in the home and in public places is a whole new area of research. You have already heard about our new research initiative on reducing frailty and injuries to older people known as "FICSIT." Several environmental interventions are being tested. These include educational programs to teach older people to identify and to avoid risk environments, and the use of protective bags to reduce hip fractures in the case of falls. These environmental interventions complement the exercise programs designed to improve physical performance and functioning.

At NIA, we have come to a new threshold in terms of research opportunities that relate to our national concerns about long-term care. Previous studies have taught us what questions to ask and

how to design our studies to examine the effectiveness of different models of care. The issues I have discussed today—family caregiving, in-home care and elder friendly environments-touch the day-to-day lives of older people and their caregivers.

Within these broad areas, there are some special concerns. For example, we know especially little about the long-term care needs of previously ignored populations. We are giving particular emphasis to the problems of the oldest old, racial and ethnic minorities, people with Alzheimer's disease, older adults with mental retardation, and the rural elderly.

But much more needs to be done. Most of us will be called upon to make care giving decisions at some time in our lives. Findings in these areas can provide critical input for individual and family decisions, for professional intervention, and for broader policy initiatives.

Dr. WILLIAMS. Thank you, Dr. Ory.

I want to welcome Senator Pryor. We certainly appreciate your coming to join this briefing, Senator. We are all very much interested in hearing from you.

STATEMENT OF SENATOR DAVID PRYOR, CHAIRMAN, SPECIAL COMMITTEE ON AGING

Senator PRYOR. Thank you, Dr. Williams. Thanks to our panel, and also to our audience for being here, and the wonderful staff representatives that are here from many of the Senate offices.

I like to tell a story when we have audiences like this. The Aging Committee staff has heard this a hundred times, I guess, but I like to tell the story about a meeting not long ago where there was a man about 100 years of age, and I usually don't know how to converse well with people who have reached their hundredth birthday. He said "Do you know how old I am?" I said "No, sir, I don't." He said "I just turned 100." I said "My gosh, you have seen a lot of change, haven't you?" He said "Yes, and I've been against all of it." [Laughter.]

There is so much change going on around us. Sometimes that change is so imperceptible and it moves in certain ways in worlds that you may be familiar with, but there is certainly a world we know nothing about here on Capitol Hill. This is why the Special Committee on Aging wanted to have a very informal seminar.

We have had a series of informal seminars this year, trying to get away from the old structured hearing, where witnesses come up to the table, and two or three Senators ask a few questions and make speeches, like we are prone to do.

We thought this would be a good opportunity to meet the researchers and to find out what is going on. It will impact this generation very seriously.

We also think there has never been a bridge built between the political system that you must deal with and the world of research that we know absolutely nothing about. We don't know what you do at the National Institute on Aging. We don't know when you walk in there at 8 o'clock and leave at 5 o'clock or 6 o'clock or 10 o'clock at night what you have done that day, or what projects you are working on.

When we hear, especially as we get into the season of the budget and when we hear about research, we all gloss over it here on the Hill. We don't know where those dollars are going. We want to make certain that we can begin building that bridge even stronger.

Biomedical research we think is certainly one of the fundamental things that you are doing, and all of you are involved with it, and know so much about it. I know nothing about what has happened in the area of biomedical research. Just to have the opportunity today to be exposed to this very distinguished panel, will go a long way toward educating us, by letting us, for a few moments, stand in your shoes and look through those microscopes that you look through on a daily basis.

We are trying to get a glimpse today into your world, and your work, and what you must do to carry out the mandates of the political system, and the hopes of all our society. We hope to learn from you, and perhaps you may learn a little from this group about how the system works.

I know we just got home last night about 11:30, we had an extremely rancorous debate on the civil rights bill, I don't know if any of you tuned in. It was not one of the better moments in the 200-year history of the Senate. That is part of the system. So knowing what you do and how you do it, hopefully will help us do our job better.

Let me thank you all for coming and sharing your experiences with us.

Dr. WILLIAMS. Thank you very much, Senator. I commented earlier that we see our efforts as trying to bring together the scientific evidence to try and spot where the most opportunities are from a scientific point of view, and intermeshing that with society's needs, which we learn about from Congress, from the public, and from our own National Institute on Aging Advisory Council. This is the type of exchange that is critical to us.

Our last presentation will be from Dr. George Martin, who is the Scientific Director of our Intramural Research Program at our Gerontology Research Center (GRC) in Baltimore. He will give us a few comments about our intramural research efforts there.

DR. GEORGE MARTIN, SCIENTIFIC DIRECTOR, NATIONAL INSTITUTE ON AGING

Dr. MARTIN. Thank you, Dr. Williams. Senator Pryor is a hard act to follow. We are aware that Arkansas has one of the major research centers to follow the basic processes of aging.

I would like to talk about the NIH laboratories at the National Institutes of Health. The intermural research program at the Gerontology Research Center has a very important role in defining aging and aging research. It began with Nathan Shock, who was recruited to the National Institutes of Health in 1941 to work on aging.

Because he wanted a clinically based research program before the Clinical Center was built in Bethesda, Dr. Shock was stationed in the Baltimore City Hospital. Subsequently he developed the Gerontology Research Center, a Federal establishment, employing over

150 scientists involved in research on molecular, cellular, and psychological aspects of aging and age-associated disabilities.

Dr. Shock started a unique longitudinal study—the Baltimore Longitudinal Study on Aging—which over about 32 years has involved some 1,200 men and women as volunteers and participants. If one had to summarize the research findings to date, many of the so-called age changes now appear to us as if they are the result of disease, therefore preventable, rather than being something we cannot avoid.

We also have a Laboratory of Neuroscience which is presently at the Clinical Center at the NIH in Bethesda, MD. This laboratory is bringing us a clinical focus and is involved in developing a major program on Alzheimer's disease.

Let me mention a few aspects of research in the area of Alzheimer's disease. The Neuroscience Lab and Clinical Center in Bethesda recently opened a new clinical unit on dementia and aging. It is involved in studies of the diagnosis, assessment, and treatment of Alzheimer's and other forms of dementia using high-tech equipment, such as PET-scanning, which measures the metabolic activity in different parts of the brain.

Ordinarily, if we look at the affected parts of the brain in patients with Alzheimer's disease, we will find a very low level of metabolic activity. What has been found recently is that if the brain is stimulated, even in moderate cases of Alzheimer's disease, there is a considerable increase in metabolic activity. This means that the nerve cells are not dead; they are responsive, and therefore are also potentially responsive to pharmacological agents which can be tested in the same fashion.

Another finding is that there is a great deal of heterogeneity in Alzheimer's disease. It is not a single disorder, but falls into at least four classes, which can be defined by the rate of progression in different regions of the brain that are affected. One form seems to have a very low level of biopterin, which is an important cofactor and vitamin in the body. We are now putting together a clinical study to assess supplementing these individuals. This research may turn out to be a very significant lead.

We have also recently created a Molecular Neurobiology Unit which will use molecular approaches to diagnose and to assess the cellular response to Alzheimer's disease better.

We scientists at NIA believe there is no area in aging we can't approach successfully through research. I mentioned two areas in my outline. One was incontinence, where a number of scientists in our Laboratory of Behavioral Sciences have found that using biofeedback techniques can assist many individuals with incontinence in controlling their own musculature.

There are other interesting developments in that area that don't come from our laboratories, but involve injecting collagen around the sphincter and restoring the normal tissue.

There are also studies from our Laboratory of Behavioral Sciences that confirm in animals what is well-known in people, that older people have a problem in adjusting to extremes of temperature. Our scientists identified a basic defect, which is the inability of the cells in the animal to show the so-called "heat shock response." This work identifies a specific defect of aging cells. It is

responsive to various pharmacological agents. So it may be possible in the future to restore the ability of individuals to respond to deficits in heat production.

Such studies indicate that we now have the technology and knowledge to make precise identification of defects in aging.

We are also proposing a clinical research center in the Gerontology Research Center because we think the time is right for assessing a variety of interventions. Probably the best known intervention is diet restriction, which has been shown in animals, if not humans, to give an extension of life span.

What impresses us about the diet restriction model is that it essentially eliminates cancer and a variety of common degenerative diseases in the animals that are raised under these conditions. What we are trying to do in our research at the Gerontology Research Center is identify the basic underlying mechanisms, and develop an understanding of the link between cancer and senescence.

We also like the idea that gene therapy may have its greatest application in aging research in conditions such as osteoporosis and frailty. Immunological defects in the aging population are also very common, leading to increased risk of infection. We think a lot of the research that has been carried out in relation to AIDS will be directly applicable in stimulating the immune responses in older people. We are starting new initiatives in vascular disease because some 60 percent of the deaths in this country are caused by vascular disease.

There are great problems in the field of aging, but there are also great opportunities. We intend to carry out an expanded research program on aging and the diseases and disabilities associated with it. It is our goal to maintain healthy aging, and to reduce age-associated disabilities.

Thank you.

Dr. WILLIAMS. Thank you very much, Dr. Martin.

That concludes our formal presentations. We welcome questions—to any of us—or comments. We are open to anything you may want to raise.

DIANE LIFSEY

Ms. LIFSEY. I want to ask a question of Dr. Claman. There was some research you are doing?

Dr. CLAMAN. The research that all three of us on this side of the table are involved with is what is called extramural research. This is research that is actually conducted at universities and institutions around the country. Our jobs are to stimulate more research at the university level, and also to manage that research. What I was speaking about was research that is actually being conducted at universities throughout the country.

Some of them are longitudinal studies, and we do encourage people to do longitudinal studies. It is one way of getting at certain questions. People do have access to the data from the Baltimore Longitudinal Study on Aging. Researchers from all over the country are able to use that research, it is actually a national resource.

Dr. WILLIAMS. I would like to ask people to identify themselves as they speak, so that we can keep a record.

I want to add to this comment that about 80 percent of our funds go through the extramural route, and about 15 percent go into the intermural Gerontology Research, and about 5 percent is administrative and management.

MARY WAKEFIELD

Ms. WAKEFIELD. I'm Mary Wakefield, from Senator Burdick's office.

Dr. Williams, there has been a lot of diversity in the focus of research topics that your panels have presented this morning. On the other hand, some of what I have read over the last few months seems to suggest that there is some tradeoff here, that the National Institute on Aging perhaps spends a little too much of its resources on Alzheimer's, and not enough on some of the other research topic areas.

Would you comment on that, based on your own experience?

Dr. WILLIAMS. It is absolutely clear that we give a high priority to Alzheimer's research. About one-third of our funds go into Alzheimer's research. This is about two-thirds or three-quarters of all Federal investment in Alzheimer's research, NIA is the major focus—we are the coordinating office for all Alzheimer's disease research as well.

Yet, this investment—we have about $75 million invested in Alzheimer's research this year, with a total Federal investment of about $120 million, is only about two-tenths of a percent of the cost of Alzheimer's disease and care each year. It is still a very tiny fragment of the investment we are making in care. That is only going to change for the worse.

My view is that we simply have to solve the problem of Alzheimer's disease through research in this century. We have 10 years or less to accomplish this. I think every penny we can invest in this is extremely important.

At the same time, there are obviously a lot of other important fields. In fact, what has happened as our Institute has grown is that there has been overall growth in our funding and what Congress has done is add extra funds for Alzheimer's research. So other areas have not suffered in terms of growth. But the Alzheimer's field has received special add-on funds. I think that's the way societal judgments are made, when society sees an area needs some special attention, the support usually comes.

I would be much more concerned if we were pressed to invade research support for other areas at the expense of this one, but that has not happened.

CHRIS WILLIAMS

Ms. WILLIAMS. I'm Chris Williams, with Senator Mitchell's office.

We have been very involved in developing a new agency to help do policy research. We are very interested in the outcomes of research for the aging population. We are particularly interested in expanding from that, going to acute care, looking at the management of chronic conditions in the elderly. Are you doing anything in that area?

Dr. WILLIAMS. Certainly. I think this is a very important area. We are actually working collaboratively at our staff level with the new Agency for Health Care Policy and Research, and looking at some of the issues of how we can measure and document outcomes across the older whole population, inasmuch as the whole issue deals with older people, because these Federal concerns are funded mainly with Medicare funds. Most of the issues that are being raised in this agency for outcome-related studies are actually dealing with older people, and we are working closely with them.

Specifically, the impact of what we could do in new initiatives in the chronic long-term area is a very important challenge. For example, we do have some demonstration projects that show that community-based long-term care, home care, at least in some instances has been more effective in helping people stay out of hospitals and nursing homes than others. I think we can learn from further research about just what types of programs can be most effective. This is one kind of outcome, how to avoid hospitalization, as well as how to maintain good health.

One other area I would emphasize is that of rehabilitative efforts, where the goal is to restore as much as possible lost function. That is a very important topic we are working with them on.

BEN CHU

Mr. CHU. I'm Ben Chu from Bill Bradley's office. It seems to me that a lot of the thrust of research, not all of it, but a lot of it, is aimed toward some pharmacological approach. I find that a little disturbing—maybe there is no way out of this—but I do find it a little disturbing that the man of the future will start taking, at the age of 50, growth hormones or muscle mass stimulators, or other drugs to help promote sleep, and something to stave off all the carcinogens in our diet, et cetera.

It seems to me that if that is true, what are the implications—given the fact that we can identify those people who are going to be subject to Alzheimer's, still people are going to have to take a whole host of drugs.

Dr. WILLIAMS. This is a very fair question, and I would like to comment on it. Maybe Dr. Sprott will have some comment on it, also.

I am concerned, I certainly want to try to see that we keep our priorities clear, that we look first of all at ways to help people maintain good health and function on their own, without the benefit of pharmacological agents. We give a great deal of priority to research involving exercise and nutrition. One of the most important areas in my view over the last few years has been the attention given to the benefits of exercise in older people.

There is some very impressive research showing how much this can benefit them in terms of minimizing bone loss, increasing muscle strength. There was a study this year showing marked improvement in 90-year-old people in muscle strength and function, other studies in older persons show how exercise improves body lipids and glucose tolerance—so many ways that exercise has great benefit.

This, plus a good lifestyle—such as avoiding smoking, and limiting or abstaining from alcohol consumption are high priorities.

On the other hand, as you say, there are people who do need some medication. One of the areas I think will be most interesting to see develop are growth factors, normal growth factors that we are finding in the brain, and bone growth factors. I think if we learn how to manipulate these, or give them, or encourage them, I would consider this more normal encouragement, rather than so much pharmacology.

But in the last analysis, some people certainly will need medications. We are interested there—I know Senator Pryor is interested—in seeing that we use medications properly, that we don't overuse them.

Dr. SPROTT. I think one of the major miracles you refer to is that one of the major long-term debilitating diseases we are talking about is the result of lifestyle choices. We have two problems. One, a chunk of the population made its lifestyle choices 40 years ago, and we now have to deal with the consequences of that. We may have to do that pharmacologically, because it is too late to convince them that a lifestyle change will give them a different kind of functioning later.

Hopefully we will convert the population to making those early lifestyle choices for those who are young enough to do it, and they won't need the pharmacology later. When we do the pharmacology, we will learn about basic mechanisms, so we can convince younger people that a lifestyle change makes sense.

Dr. MARTIN. Maybe we could go as far as getting hair follicles put back in. [Laughter.]

Dr. WILLIAMS. You know, God made two kinds of people. He made some people with perfect heads, and the rest he put hair on. [Laughter.]

SHARON HALFANT

Ms. HALFANT. I'm Sharon Halfant, from Senator Specter's office.

I wondered what dialogue you have had with the medical community not involved with research who are doctors that when patients come to them, they prescribe medications that often result in a lot of difficult ailments because of mixing all these medications.

Dr. ORY. We are currently funding a study at Johns Hopkins on drug management that examines doctor-patient interactions around drug-giving. The goal is to make health professionals more aware of possible drug side effects and to improve their communication with patients. Sometimes patients come in thinking they don't get good care unless they get a prescription. So we need to understand what is happening both from the provider's perspective, as well as from the patient's.

Dr. SPROTT. I was going to ask you to comment, Dr. Williams, on why we use consensus conferences and why we need geriatric assessment.

Dr. WILLIAMS. There are many ways in which we need to try to tackle this problem. The NIH convenes consensus development conferences when there appears to be a new body of knowledge that the practicing physicians ought to be aware of. We have had sever-

al of those in the last few years, one on the differential diagnoses of dementia, and others on the role of geriatric assessment in management of older people.

There is a whole series of others where the specific goal is to develop and lay out the new knowledge, and transmit it to the practicing professions. These conference reports appear in the major medical journals. Our own information staff does a great deal of dissemination as well, but we need to go further, just as Dr. Ory was implying. We need to understand better what the problems are in teaching physicians and the public about the proper use of medications.

One example of a study that we have had a hand in is at Harvard also, where Dr. Jerry Arven has shown that the single best way to change a physician's practice is a one-to-one relationship. That may be a fairly expensive way to go about it; pharmaceutical companies do it all the time. That's very critical, really, to try to help a physician understand that he or she needs to be more careful.

Finally, I think individuals—one thing that we stress is that an older person, or any person, should go over all of their medications with a doctor. If they come in and if the doctors see a bagful of medication, they will think twice about adding any more to that bag. It is really a big challenge, and it needs a lot of work.

Ms. HALFANT. Is there any kind of effort going on in your organization to do outreach to medical communities?

Dr. WILLIAMS. Yes. Part of our information office has that specific role, to send communications to doctors and then we have regular columns in many journals.

Ms. HALFANT. What about studies that show the effects of medication, and if you are giving someone medication for high blood pressure, being aware of combining other medications with that?

Dr. WILLIAMS. As I just said briefly in my opening remarks, we have taken on a special initiative this year inviting research applications on pharmacology and aging, some of which will deal specifically with this question of cross-reaction of drugs. Not much of that has been done, quite honestly, and it needs to be done. As I mentioned, we have over 100 applications for research to support.

Senator PRYOR. I would like to share this. I discovered by accident down in Arkansas some months ago a wonderful place called GAC, the Geriatric Assessment Clinic. I was invited there to cut the ribbon on the place, and I didn't know much about it. Once I got there, I became fascinated with this little place. It's probably the size of this room.

GAC is located in the northwestern part of our State, near Rodgers, AR. It is operated by the Catholic Church. They have a team of specialists, who analyze the patient by finding out what drugs they are taking, find out what their diet consists of, and give them a total physical workup. They also have psychiatrists and psychologists there.

In the course of about a day or 2 days at most, a total chart and history for this individual is compiled.

Are there a lot of these kinds of places around the country?

Dr. WILLIAMS. Yes, sir. This is growing quite rapidly. I personally had an opportunity to help start one of the first of these when I

was back in Rochester, NY. It is growing, fortunately, and I think it is a very valuable thing. Not everybody needs it, but when there are special or complicated problems, they are invaluable.

Senator PRYOR. They have since that time added a day care center as a part of the place. It is really very impressive.

I think with that, I will have to take my leave.

Dr. WILLIAMS. Thank you for coming, Senator Pryor.

Senator PRYOR. Thank you for holding this conference.

Dr. MARTIN. I think geriatric medicine is much more important in our medical schools as a specialty. It will have a big impact.

Dr. WILLIAMS. Yes, it will.

Are there other questions?

LYNNE KAMINS

Ms. KAMINS. I am Lynne Kamins, from the Center for Advanced Studies in Immunology and Aging.

Dr. Claman mentioned that in order to understand what we are dealing with, we need for each person to understand what is normal, that is easy to understand.

Dr. Sprott mentioned that there is a tremendous variance in chronological aging. My thought was, I wonder if there is any interest at the NIA in studying a third category, normal disease and then supernormal, or however you would like to categorize it. I am thinking back to when former President Reagan was shot, the comment was that on the inside, he was like a much younger person.

I was wondering if at the NIA, there is an interest in studying people whose physiology seems to be more than typical.

Dr. WILLIAMS. That is a very provocative question. I guess that is one way in which the subjects of the Baltimore Longitudinal Study of Aging might qualify, because they have been volunteers, and many of them, at least, have turned out to be astonishingly healthy.

But I am not sure we're aware that any of us has tried to go out and get a supernormal group. That would come back in part to this whole question of how to define supernormal.

Dr. MARTIN. A masters outreach.

Dr. WILLIAMS. Yes, we are doing studies as a masters outreach, that is a group, exactly.

Dr. SPROTT. I was going to mention that same population. These are people in their 60's, 70's, 80's, and 90's, who are still running marathons and doing activities like that.

Dr. CLAMAN. I wanted to clarify a little bit of what I said. I think we need to find a range of normalcy, and what we are all probably trying to indicate is there probably is a great range within each domain. There is probably not going to be one single target point based on chronological age. The biomarkers program and projects in our own program are looking for a variety of ways of determining the status of various organ systems and in my case, this means the brain and brain functions.

Dr. WILLIAMS. One slide that I use, you reminded me when you mentioned the athletes, shows the maximum aerobic capacity which people achieve in fitness programs, for example. There is a general downward trend in average samplings of people with age.

But then masters athletes are way up here, just as high as young people. So it shows that it is people. Now that is a self-selected group of older people, but still, it is possible.

Ms. WAKEFIELD. When you look at the populations that are included in the studies that NIA is conducting, do you feel your populations adequately represent both gender and minorities? You are probably as aware as most of the people in this room that a lot of concern has been leveled at the NIH by their overemphasis on males, older males or middle-aged males, and not enough emphasis and inclusion of females or minority populations.

How does NIA fare on that?

Dr. WILLIAMS. Dr. Sprott has some comments on that.

Dr. SPROTT. It's a fair question, but I think if you think about the problems of aging, the answer is probably relatively obvious for this institute as well. Many of the problems we are talking about are the problems of women. So in fact, if you look at the populations we study across the board, roughly 53 percent of the subjects in our clinical trials are women. So we spend about $28 million per year on clinical research as a whole. Well over $14 million of that deals with the problems of women. Those really are aging problems.

So in that regard, our subject population very adequately represents women. We work very hard at representing minorities. There, again, we have certain kinds of special interests, because there are big differences in minorities' susceptibility to problems. For example, black women don't get hip fractures. It is interesting to know why that is so. Black males, on the other hand, are much more subject to high blood pressure and its consequences. So we are looking at those kinds of variables as well.

Dr. WILLIAMS. This is essential in our research. We held a 2-day symposium about 2 years ago on gender differences in aging. That helped define some of the research work. We want to look at how to understand the differences. Why do women live longer than men?

Dr. SPROTT. About half of that difference is probably environmental, and the other half is basic biology. We want to understand both.

Ms. LIFSEY. The Baltimore Longitudinal Study has much more on that.

Dr. MARTIN. It's about 50–50. Women joined the study in 1977 and 1978 and they are now approaching about 45 percent, and should cross the margin soon.

Dr. WILLIAMS. I just wanted to mention for some that have come late, there is a fair amount of literature in the back for anyone who wants it. I guess we should wind up fairly soon, we can take another question or two.

JENNIFER TILLER

Ms. TILLER. I'm Jennifer Tiller, from Senator Kassebaum's office. I am wondering what your organization does to encourage medical students or people to get interested in geriatrics. It seems there is a great many of our population entering that phase.

Dr. WILLIAMS. This is extremely important from my perspective, I think for all of us. Our main explicit contributions thus far have been made at the faculty level, to try to build up faculty members who are committed to and competent in aging research, or aging issues, and aging knowledge, and in geriatric medicine. We do that through training grant awards, and awards to individual fellows, and then for career awards for junior faculty, on up into middle faculty levels. We have more than doubled our support for these types of faculty positions in the last 5 to 7 years.

We still think we should probably double it again, to try to help populate adequately all medical schools with faculty who are committed to this field. There is enough of a nucleus to really have an impact. Virtually all medical schools now have some teaching in geriatrics, and over 90 percent have a reasonably organized program. But it is still pretty minimal. It is a big challenge. That's where we are going.

We also try to provide our literature. But I think it comes down to getting the faculty in the schools. We welcome ideas as to how to go about that.

I want to mention before we leave that Ms. Mittelman and our staff have talked about the question of whether it would be useful to have some more briefings or informal seminars to go into more depth about some of the topics raised here or other topics.

I would like to say that we would be very glad to work with the Senate Special Committee on Aging to arrange informal discussions in more depth on any aspect of aging research. We would like to leave that open for passing on your ideas to the Aging Committee staff.

If there are any other questions, we will take them.

If not, Ms. Mittelman, we certainly appreciate your help in getting this together. Thank you all again for coming this morning.

[Whereupon, at 10:54 a.m. the seminar was adjourned.]

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